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## Using Structural Equation Modeling to Understand the Role of Informal and Formal Supports on the Well-being of Caregivers of Persons with Dementia

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**SEDAP Research Paper No. 95**

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# USING STRUCTURAL EQUATION MODELING TO UNDERSTAND THE ROLE OF INFORMAL AND FORMAL SUPPORTS ON THE WELL-BEING OF CAREGIVERS OF PERSONS WITH DEMENTIA

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SEDAP Research Paper No. 95

March 2003

The Program for Research on Social and Economic Dimensions of an Aging Population (SEDAP) is an interdisciplinary research program centred at McMaster University with participants at the University of British Columbia, Queen's University, Univérsité de Montréal, and the University of Toronto. It has support from the Social Sciences and Humanities Research Council of Canada under the Major Collaborative Research Initiatives Program, and further support from Statistics Canada, the Canadian Institute for Health Information, and participating universities. The SEDAP Research Paper series provides a vehicle for distributing the results of studies undertaken by those associated with the program. Authors take full responsibility for all expressions of opinion.

# Using Structural Equation Modeling to Understand the Role of Informal and Formal Supports on the Well-being of Caregivers of Persons with Dementia

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Keywords: Caregiver, Well-being, Dementia. Informal support, Formal Support, Canadian Study on Health & Aging, Structural Equation Modelling.

Running title: Health of caregivers of people with dementia

**Acknowledgements:** This project was supported by SEDAP program of research funded by SSHRC. Dr. Raina holds National Health Scholar Award from CIHR/NHRDP. We would also like to thank Fulvia Baldassarre for help in the preparation of this article.

## ABSTRACT:

This study examined the direct and indirect relationships based on stress process conceptual model between informal caregiver characteristics, source of caregiver stress and informal and formal support on the well-being of the caregivers of persons with dementia. Structural Equation Modeling was used to test specific hypotheses based on 327 caregivers of study subjects with dementia who were living in the community and that were derived from the first wave of the Canadian Study of Health and Aging. Our findings show that the negative impact of the increase in care recipient's disability on psychological well-being of the caregiver was moderated mostly by the use of informal support systems, and marginally by formal support systems. The use of informal support by caregivers resulted in a decreased use of formal supports. The relationship between caregiver characteristics and psychological health was mediated by the formal support but not by informal support systems.

## Introduction

The age-standardized incidence of dementia in Canada has been estimated at 21.8 per thousand for females and 19.1 per thousand for males[1]. Dementia results in deterioration of physical and mental function resulting in dependency for the individuals and care responsibilities for their family and friends[2]. Persons with advanced dementia require constant and specialized homecare and medical services. This is particularly important in light of the increasing life expectancy[3] and the resulting increase in the proportion of Canadians at risk of developing dementia.

The task of a caregiver is multifaceted and complex; a stressful life situation that can lead to devastating consequences[4-6]. Like an occupational career, the notion of caregiving as a career connotes a dynamic process, where an individual moves through a series of stages, requiring adaptation and restructuring of responsibility over time[4,6,7]. These stages might include 1) anticipation for and acquisition of the caregiver role, 2) performance of tasks, and responsibilities, and 3) eventual exit from the role[4,6,7]. Unlike a career, however, the caregiver role is usually not planned or chosen and is generally not seen as an appealing pursuit for the future.

Although the stress and risk of poor health has been established in the caregivers of persons with dementia, there is less knowledge about the factors that increase stress, and a need to establish interventions to address the suffering of the caregivers. Understanding factors that affect caregiver stress may inform interventions that will maintain their role. It is critically important that policy makers, researchers and advocacy groups help family caregivers to maintain their roles. If we neglect this, it may

result in earlier and increased rates of admission to institutional care of person with dementia.

Why some caregivers cope and others do not is not fully understood? Stress has been conceived as the balance between *external* environment demands and the perceived *internal* ability to respond, or when the demands *prevent* the pursuit of other life objectives[4,8,9]. Modifying factors include 1) the characteristics of the caregiver (such as age, marital status, coping ability)[10,11], 2) characteristics of the recipient (such as the degree of disability)[10,12], 3) their shared history[4], 4) social factors (such as access to social networks, social support, etc)[8,10], 5) economic factors (such as SES level, ability to access formal care, etc)[4,10], and 6) cultural context[4]. Each of these factors can enhance or alleviate stress; they suggest that stress occurs in a broader context than the provision of care for a person with dementia.

Several theoretical models describe the stress process in caregivers[9,13,14]. Although these models provide some insight into stress of caregivers, previous analyses have used traditional approaches to examining the relationship between a factor and the outcome after adjusting for other variables. The approach of estimating the “independent” or “direct effects” of the care recipient’s disability on the caregiver’s health is limited because a) single factor changes are rare outside of the context of constrained experimental situations, b) assumptions of linear or additive relationships and perfect measurements rarely hold, and c) they do not provide a complete perspective by not examining direct and indirect pathways occurring between predictor variables and health outcomes. A more complex analytical approach is needed to

understand direct or indirect effects of factors simultaneously within a theory-based multidimensional model.

This research examined the direct and indirect associations between informal caregiver characteristics, source of caregiver stress and informal and formal support on the well-being of the caregivers of the elderly people with dementia. The conceptual model that guided this research is shown in Figure 1 and is based on the Stress Process Model[9]. The stressors in this model are a function of the care recipients' disability and the demands of the caregiving role itself. The potential effects of the stress involved in the caregiving role highlight an existence of the complex stress process[4,9]. This conceptualization includes formal and informal support as moderating factors, which determine how people are affected differently by the same stressors, and may help sustain the caregiver and lessen the effect of the stressors. In our conceptualization, the stress is manifested in health-related outcomes such as psychological and physical well-being[12,15-17].

Specifically, we hypothesized that an increase in care recipient's disability (CR disability) would be directly associated with poor physical and psychological well-being of primary caregivers. However, the direct relationship between CR disability and well-being would be mediated by informal and formal support factors. We also hypothesized that caregiver characteristics would be directly associated with physical and psychological well-being and that this direct relationship would be mediated by informal and formal support.

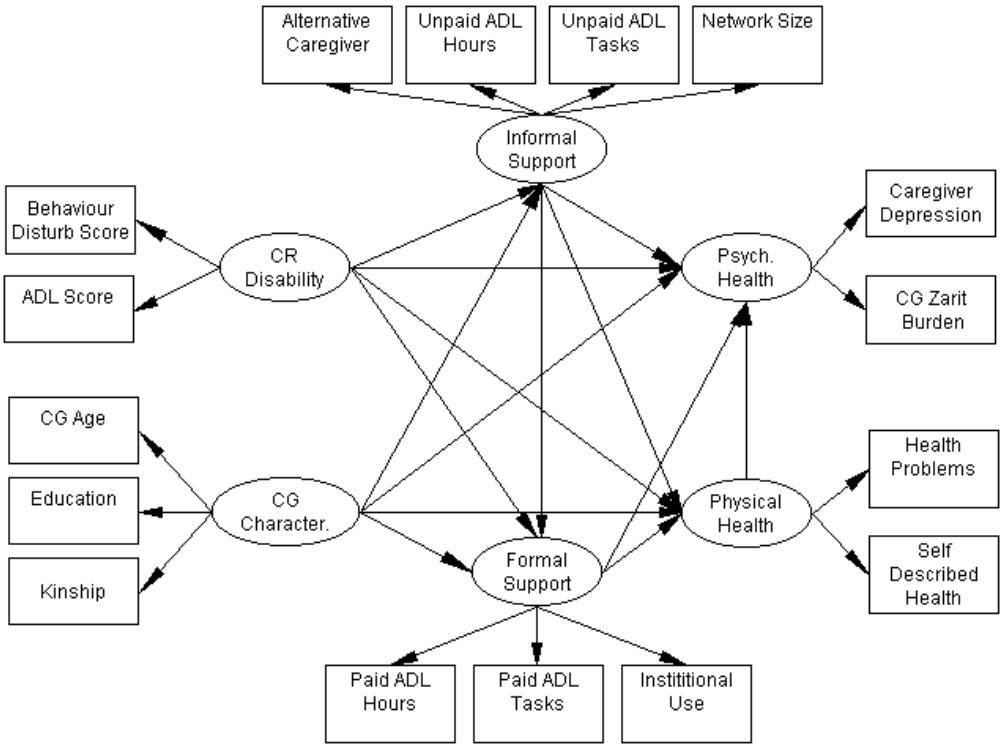


**Figure 1**. Hypothesized model of caregiver stress, support and health relationships. CR Disability = Care recipient disability; CG Character. = Care giver characteristics; Psych. Health = Psychological health; CG Age = Care giver age.

## Methods

The methods of Canadian Study of Health and Aging (CHSA) have been described in detail elsewhere[2,10,18]. The CSHA-1 caregiver sample included the caregivers of 1686 index subjects by place of residence, diagnosis and type of caregivers seniors. Of these, the present analyses were done on 327 informal caregivers of study subjects with dementia who were living in the community (see Table 1 in [10]). The caregiver study involved an interview with the primary caregiver of each index subject; caregivers were identified through discussion with index subject and their family.

### Data Collection

#### *Recipients of Care*

The interview with the caregiver collected information on the care recipient's need for assistance in basic activities of daily living (ADL) and instrumental activities of daily living (IADL) using the 14-item scale developed for the Older Americans Resources and Services (OARS) project[19,20]. The ADL score was a summed score ranging between 0 and 14 with larger scores reflecting more problems in their daily function. Caregivers of people with dementia completed the Dementia Behavior Disturbance (DBD) scale to record the frequency of behavior problems. This scale included 28 items and scores ranged from 0 to 112, with higher scores indicating more problems. It has a reported co-efficient $\alpha$ of 0.84[5].

***Informal Primary Caregiver***

Data were collected on the caregiver's age, sex, education status and kinship to the index subject. Demographic information was collected for others who provided assistance, and availability of alternate arrangements of support for the index subject was also recorded. Physical health of the caregivers was assessed using a list of 12 self-reported chronic health conditions. The responses (yes/no) from 12 chronic conditions were summed with higher scores indicating greater health problems[21]. Self-rated health was assessed using a single global question "How would you say your health is these days?" using a 5-point response scale[20]. A score of 1 indicated "very good" health and 5 "very poor" health. Depression was evaluated using the Center for Epidemiologic Studies Depression questionnaire (CES-D)[22]. Possible scores range from 0 to 60 and scores of 16 or above were taken to indicate depression. For those caring for a person with dementia, the caregiver's feelings of distress were recorded using Zarit's 22-item Burden Interview[23]; scores range from 0 to 84 with high scores indicating more burden.

Informal and formal support was represented by four and three variables respectively, as shown in Table 1.

**Table 1:** Descriptions of informal and formal support.

| **Measurement Variable** | **Description of Variable** | **Scoring Characteristics** |
|---|---|---|
| unpaid Informal | Caregiver report of the number of ADL tasks provided by other family and friends | 0 to 14; 14 items; high scores indicates more help. |
| Alternative Caregiver | Question: "Who would take over your role of caring for care recipient if you were not available?" | Answers were coded as '1'- family or '0'- formal service, don't know or no one. |
| Total unpaid ADL support | Caregiver report of the total hours per month that family and friends spend helping the recipient with their ADL's | 0 to 288 hrs, up to 3 helpers; high scores indicates more help from informal helps. |
| Network size | Number of people living with the caregiver and number of close relatives and friends within an hour drive | 0 to 96; high scores indicates more people involved in care. |
| Paid ADL | Caregiver report of the number of ADL tasks provided by paid service | 0 to 14; 14 items; high scores indicates more help. |
| Institutional use | Caregiver report of the number of use of institution services | 0 to 8; 8 subscales; high scores indicates more service uses. |
| Paid ADL help | Caregiver report of the total hours per month of paid help in ADL | 0 to 271 hrs, up to 3 helpers; high scores indicates more help from paid services. |

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### *Statistical Analysis*

Descriptive statistics were calculated for all variables in the analysis. Structural Equation Modeling (SEM) was used to test specific hypotheses outlined in our conceptual model. This model involves a two-step process where observed variables are hypothesized to measure the constructs and are tested using confirmatory factor analysis (measurement model). The second step focuses on testing hypotheses about causal relationships among the variables in the structural model. Several model diagnostic approaches were used to assess integrity of each phase of the SEM and the variables included in the model[24-27]. We used the PROC CALIS procedure in SAS version 8.2, using covariance matrices and Generalized Least Squares (GLS) estimation method. For SEM analysis, some of the observed variables were also log transformed and are shown in Table 2. The data for 36 missing values were imputed using mean replacement method.

## Results

### Description of the Sample

The mean age of caregivers was 61.7 years and 82.2 years for the care recipients. Women comprised 79.2% (n = 259) and men 20.8% (n = 68) of the caregivers. In terms of the caregiver's relationship to the care recipient 32.72% (n = 107) were daughters, 24.46% (n= 80) wives, 24.16% (n = 79) sisters, 11% (n = 36) sons, and 7.65% (n = 25) husbands. The mean ADL score for care recipients was 6.42 (3.77). The mean CES-D depression score for caregivers was 8.83(sd=8.90) and for

health problems was 2.58(sd=1.82), whereas the mean for self-described health problems was 1.79 (sd=0.72).

Table 2 details the range, mean and standard deviation of the observed variables. The bivariate correlations for these variables are shown in Table 3.

**Table 2**: Range, Mean, Standard Deviation and Sample Size for Observed Variables

| | Min/max | Mean | SD | N |
|---|---|---|---|---|
| Caregiver Depression* | 0 – 41 | 8.83 | 8.90 | 321 |
| Caregiver Zarit Burden | 0 – 79 | 22.38 | 16.23 | 312 |
| Health Problems* | 0 – 8 | 2.58 | 1.82 | 315 |
| Self Described Health* | 1 - 5 | 1.79 | 0.72 | 315 |
| Unpaid Informal | 0 – 13 | 1.54 | 2.46 | 327 |
| Alternative Caregiver | 0 – 1 | 0.60 | 0.49 | 326 |
| Total Unpaid ADL Support* | 0 – 288 | 15.93 | 41.90 | 327 |
| Network Size | 0 – 96 | 7.67 | 10.92 | 325 |
| Paid ADL | 0 - 14 | 1.42 | 2.38 | 327 |
| Institutional Use | 0 -6 | 1.22 | 1.39 | 325 |
| Paid ADL Help* | 0 - 271 | 11.01 | 33.04 | 327 |
| ADL Score | 0 –14 | 6.42 | 3.77 | 327 |
| Behavior Disturbance Score* | 0 –76 | 16.86 | 13.88 | 311 |
| Caregiver Age | 26-90 | 61.69 | 13.38 | 324 |
| Kinship | 2-5 | 3.69 | 1.06 | 327 |
| Education | 0 - 24 | 11.17 | 3.81 | 322 |

* = Distribution non-normal, data transformed

**Table 3**: Correlations of Observed Variables, (N= 327).

| | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | CG Depression | 1 | | | | | | | | | | | | | | | |
| 2 | CG Zarit Burden | .61 | 1 | | | | | | | | | | | | | | |
| 3 | Health Problems | .51 | .30 | 1 | | | | | | | | | | | | | |
| 4 | Self Described Health | .43 | .22 | .52 | 1 | | | | | | | | | | | | |
| 5 | Unpaid Informal | -.04 | .05 | .01 | -.01 | 1 | | | | | | | | | | | |
| 6 | Total Unpaid ADL Support | -.08 | -.02 | -.04 | -.01 | .77 | 1 | | | | | | | | | | |
| 7 | Alternative Caregiver | -.08 | -.12 | -.12 | -15 | -.06 | -.09 | 1 | | | | | | | | | |
| 8 | Network Size | .00 | -.03 | .04 | -.01 | .01 | .12 | -.04 | 1 | | | | | | | | |
| 9 | Paid ADL | -.08 | -.02 | .02 | .06 | -.12 | -.10 | -.07 | -.04 | 1 | | | | | | | |
| 10 | Paid ADL Help | -.02 | .03 | .04 | .07 | -.07 | -.06 | -.07 | .04 | .69 | 1 | | | | | | |
| 11 | Institutional Use | .04 | .16 | .06 | .10 | -.02 | -.06 | -.08 | -.15 | .47 | .30 | 1 | | | | | |
| 12 | Behaviour Disturbance Score | .35 | .64 | .19 | .11 | .17 | .16 | -.04 | .03 | .05 | .10 | .12 | 1 | | | | |
| 13 | ADL score | .16 | .28 | .09 | .07 | .28 | .25 | -.23 | .08 | .39 | .31 | .30 | .37 | 1 | | | |
| 14 | Caregiver Age | .15 | -.03 | .24 | .21 | -.14 | -.14 | -.10 | .05 | -.04 | -.01 | .02 | -.13 | -.02 | 1 | | |
| 15 | Education | -.21 | -.04 | -.26 | -.26 | .00 | -.02 | .08 | -.08 | .20 | .14 | .11 | .03 | .06 | -.33 | 1 | |
| 16 | Kinship | .29 | .14 | .26 | .19 | -.26 | -.15 | -.06 | .20 | -.27 | -.09 | -.11 | .01 | .09 | .48 | -.36 | 1 |

## Structural Equation Modelling

### *Measurement Model*

The initially hypothesized model in Figure 2 includes the observed variables for each latent construct and the predicted paths among the latent structural variables. Confirmatory factor analysis was used to test the measurement model. Based on the results of the initial measurement model few modifications were made to improve the performance of the model. First, we dropped three variables ("Zarit burden", "kinship" and "network size") from the model because of either convergence problems or small factor loadings. Two additional variables, "Is there anyone to takeover care giving?" and "caregiver depression" were specified as single variables in the structural model. As a result, psychological health was measured in the structural model with the caregiver depression variable and alternative source of caregiving was hypothesized as a measure of potential social support.

The revised measurement model indicated a good fit with $\chi^2$ of 72.37($p = .01$), goodness of fit index (GFI) of 0.97, and root mean squared error of approximation (RMSEA) of 0.04. The final measurement model is shown in Figure 3 and includes the factor loadings of directly observed variables on the five latent constructs. All loadings were substantial in magnitude, and significantly different from zero, indicating that latent constructs were adequately operationalized by the observed variables.

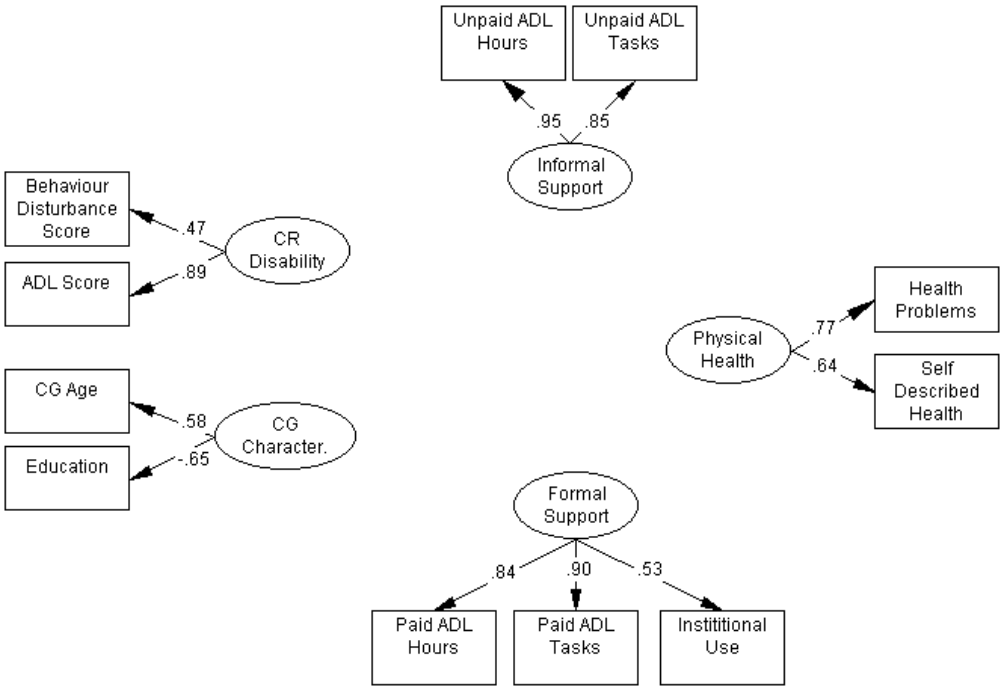


**Figure 2**. Measurement model of latent constructs and observed variables. Values represent standardized factor loadings and all are statistically significant (p = 0.05). CR Disability = Care recipient disability; CG Character. = Caregiver characteristics; Psych. Health = Psychological health; CG Age = Caregiver age. Psychological health and potential support were not included because they were measured with one observed variable.

**The Structural Model**

Figure 3 displays the standardized estimates for the hypothesized relationships among the latent constructs, which are indicated by the elliptical shapes. Overall, the model appeared to perform without any problems. The goodness of fit indices demonstrated a reasonable fit and none of the standardized coefficient estimates were greater than 1. The goodness of fit statistics fell within acceptable ranges. The chi-square degrees of freedom ratio was less than 2 and the RMSEA was below 0.08, which indicates an acceptable fit. The $\chi^2$ for the structural model was 79.01(p=0.01), the goodness of fit index (GFI) was 0.96, and the RMSEA was 0.04.

In general, the results of the structural model showed the greatest support for the prediction that psychological health, measured in terms of caregiver depression, was explained by physical health, dementia behavioral disturbance score, and informal support. There was a moderate amount of support for the hypothesis that care recipient disability, caregiver characteristics, and informal support explained formal support. Physical health of the caregivers displayed a large effect on the caregiver depression score. Figure 3 shows the structural regression coeffiecients and the corresponding $R^2$ statistics. For example, psychological health has an $R^2$ of 0.44, suggesting that physical health, informal and formal support, and CR disability accounted for 44% of the variance in psychological health. This $R^2$ value amounted to the largest proportion of explained variation in the final model.

With respect to specific hypothesized paths in this analysis, CR disability was significantly associated with physical health, psychological health of the caregiver, and

informal and formal supports. Caregiver characteristics were significantly associated with physical health of the caregiver, potential social support, and formal support. There was no statistically significant relationship between formal support and physical health. The use of informal support by caregivers resulted in a decreased use of formal supports.

In relation to our first hypothesis, increase in CR's disability was associated with a decrease in (direct hypothesis) physical ($\beta$=0.20) and psychological ($\beta$=0.22) well-being of primary caregivers respectively (Figure 3). The poor physical health associated with increase in CR's disability was not significantly modified by the use of informal and formal supports (non-significant paths are not shown in Figure 3). However, the increase in CR's disability was associated with increased ($\beta$=0.34) use of informal support, and in turn, increased use of informal support was associated with better psychological well-being of primary caregivers ($\beta$= -0.14). Similarly, CR's disability was associated with increased use of formal support ($\beta$=0.57), and in turn, increased use of formal support was associated with better psychological well-being of caregivers ($\beta$=-0.13) but this relationship was marginally significant on one tailed t-test. Despite its marginal significance, the path from formal support to psychological health was left in the model because of its contribution to the overall fit of the structural model. In other words, the negative impact of the increase in care recipient's disability on psychological well-being of the caregiver was moderated by the use of informal supports, but perhaps marginally by formal supports. The pre-disposing factors such as caregiver characteristics were also associated with physical health ($\beta$= 0.53) but this effect was not mediated by informal and formal supports. On the other hand, no statistically

significant direct association was observed between caregiver characteristics and psychological well-being. However, an increase in caregivers characteristics, such as age and education, was associated with lower use of formal support ($\beta$= -0.20).

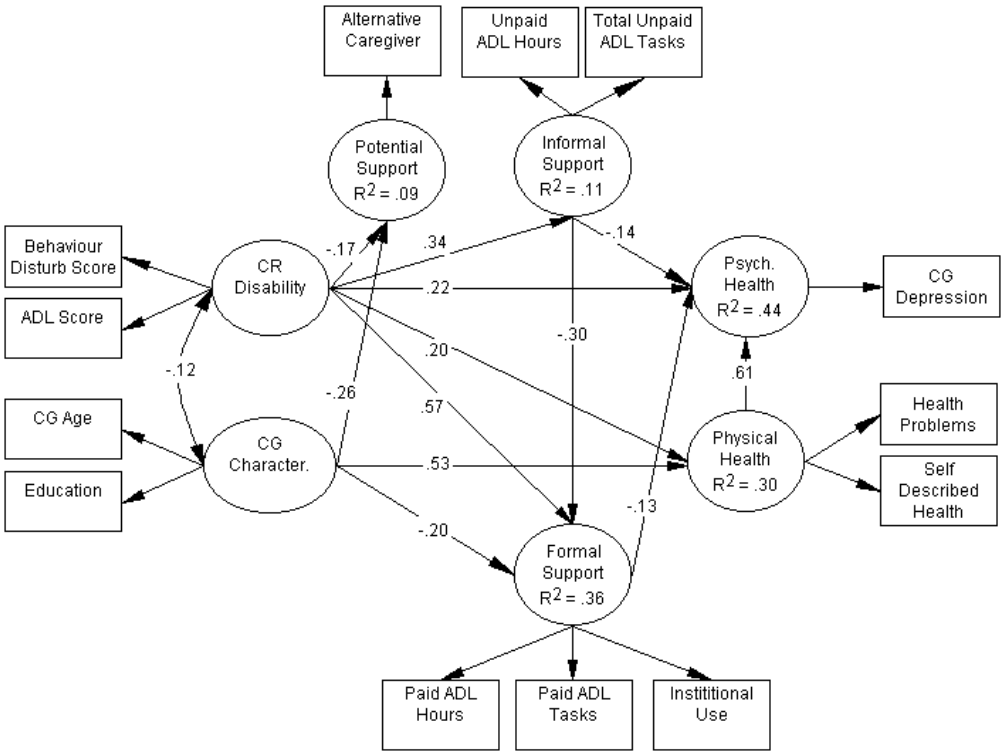


Figure 3. Structural model of caregiver stress, support and health relationships containing statistically significant (p = 0.05) standardized coefficient estimates. $R^2$ represents the amount of variance explained in the structural variable by the independent structural variables. CR Disability = Care recipient disability; CG Character. = Caregiver characteristics; Psych. Health = Psychological health.

## Discussion

This study examined the direct and indirect relationships based on a conceptual model between a series of important variables recognized as important to the caregiving process and their impact on caregiver's health and well-being. The conceptual model represents tenets of the Stress Process model and points out the complexities of caregiving through the use of SEM. Our conceptual model assumed that selected caregiver characteristics would have direct and indirect effects on all other constructs in the model.

The findings of this study showed that the structural variable, potential social support, was not related to caregiver well-being. Secondly, it was found to be a construct of social support that is distinct from the latent construct of informal support. The difference in these two constructs is due to the fact that one measured perceived/potential support and the other measured actual or use of instrumental support. Our findings suggest that availability and use of instrumental support is likely to be a more important construct, as it relates to the well-being of caregivers rather than potential support. However, the perception of social support has been shown to be inversely related to burden and similarly, has also been shown to be directly related to caregiver health[28-30]. Chappell and Reid (2002)[13], using Path analysis, demonstrated that perceived social support was a mediator for caregiver well-being. In their study, perceived social support was measured using Pearlin's Social Support Scale[8], which is conceptualized as both instrumental (informal and formal support) and socio-emotional support (for example, "There is no one who really understands what I am going

through"). In our study, the instrumental aspects of social support were captured with the Informal Support latent construct. The difference between our findings and the findings of Chappell and Reid (2002)[13] may be due to other variables of potential relevance for the construct of social support, such as socio-emotional and intra-psychic factors (for example, self-esteem, mastery, coping strategies), that were not captured in our model.

Research has demonstrated that patterns of caregiver well-being and support vary according to the age, gender, relationship and socioeconomic status of the caregiver[10,31-34]. A similar finding of the direct relationship between caregiver characteristics and physical health was also observed in the present study. In addition, our findings showed that the relationship between caregiver characteristics and psychological health may be mediated by the presence and use of formal supports.

Much research has been directed to the relationship between stressors and health outcomes in caregiver research. There is evidence that increases in functional and behavioral impairments are associated with decline in physical and psychological well-being of caregivers of people with dementia[10,34-36]. However, most of the previous research examining this relationship has typically focused on the prediction of caregiver stress on well-being, and on understanding how much variance in caregiver well-being is accounted for by a range of predictor variables[10,12,35,37-40]. Rather, our analysis focused on determining the how and why it predicted well-being. Our findings showed that the CR disability was directly and indirectly related to the psychological well-being of caregivers, but is only directly related to the physical health status of caregivers.

These findings suggest that caregiver's psychological well-being might be moderated mostly by the increased use of informal supports and somewhat by formal supports.

The findings of this research suggest that if we were to develop more effective caregiver interventions programs, we need a thorough understanding of mediating resources (such as informal and formal support) so we can target our interventions programs effectively. In addition, caregiver characteristics should also be screened so we can target our interventions programs to caregiver populations who are at greatest risk. Furthermore, the findings of our study also suggest that the mediating factors included in the Stress Process model might be better at explaining the caregiver's psychological health but relatively poor in explaining the physical health of the caregivers. Therefore, future studies should examine the feasibility of developing new model that elucidates factors that may predict the physical health status of caregivers better than existing frameworks.

This study has several notable strengths including the population-based random sample of caregivers and the use of a conceptual model to base its hypotheses. However, there are few limitations inherent in the current analyses. One of the limitation relates to the use of cross-sectional rather than a longitudinal data set. A second limitation of our study is that the CSHA did not collect data that was based on any particular theoretical model. Therefore, our present analysis was could not include additional constructs such as intra-psychic factors and coping strategies. To clearly understand the causal associations within a Stress Process model, future studies

should consider longitudinal designs and also require the collection of data that is driven by a conceptual framework.

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